

Validity of the Rotterdam Symptom Checklist in Paediatric Oncology

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In order to determine the validity of the Rotterdam Symptom Checklist (RSC) for use with paediatric patients, a sample of 47 mothers with a child with acute lymphoblastic leukaemia (ALL) was asked to complete the RSC, the Play Performance Scale for Children (PPSC) and a measure of daily activity (FDI). Questionnaires were completed during routine outpatient visits. There were no effects of child age on number of symptoms reported. The physical symptom subscale of the RSC distinguished between children in terms of treatment status and

number of hospitalisations. However, the psychological symptom subscale did not distinguish between these groups. Limitations of the scale for work with children are considered. These include difficulties experienced by parents in reporting psychological symptoms for their children, and the inappropriateness of a scale developed for adults to assess children. In the absence of other measures, the RSC can be used for children, but a more developmentally appropriate measure is needed. *Med. Pediatr. Oncol.* 28:451–454, 1997. © 1997 Wiley-Liss, Inc.

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INTRODUCTION

Children with cancer experience a number of stressful procedures, many of which are associated with pain and unpleasant side effects. For example, children on treatment are likely to suffer from loss of hair, mouth ulcers and feel sick. In addition to these physical symptoms, a number of psychological symptoms may also be experienced. These can be the result of separations from the family, or communicated through the visible distress shown by parents. Given the potentially negative experiences associated with cancer and its treatment, there is a need to assess both the physical and psychological symptoms experienced by children. This becomes even more critical as physical and psychological morbidity are increasingly seen to be important in evaluations of clinical trials.

For some children, symptoms continue to be experienced after completion of therapy. These are of a different kind and hopefully less intense than those experienced on treatment. For those who have completed therapy, reported psychological symptoms are likely to include educational problems, distractibility, inability to concentrate, fear of recurrence and continued monitoring of physical symptoms.

Despite the evidence that suggests a high and continuing experience of symptomatology in paediatric cancer patients, there is no wholly satisfactory measure currently available. The most commonly used instrument is the Play Performance Scale for Children (PPSC) [1], although this has come under some criticism [2]. It is a parent-completed instrument which has the merits of being brief and easy to complete. However, it lacks discriminability for children who are relatively well and

functioning within normal limits. In many circumstances, (including comparisons of clinical trials), it is necessary to be able to make finer discriminations than is possible with the PPSC. With the increase in numbers of survivors and reports of prevalence of a range of late effects [3], it is becoming equally important to develop a tool which is appropriate for children who are on therapy but relatively well, in addition to those who have completed therapy.

Whatever the circumstances under which one wishes to assess symptoms, there is a basic choice to be made between *general* measures developed for use with children, (but not for children with cancer) and cancer-specific symptom rating scales which have been developed for use in oncology, but primarily for adults.

Most symptom checklists for children have been developed for use in general pediatric screening [4]; as such they tend to include a broad range of problem behaviours as well as physical symptoms. Instruments are often developed in the U.S. and lack wide applicability, especially when they include items to assess general problem behaviour. (A behaviour seen to be problematic in one culture is not necessarily perceived to be so in a different culture.)

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TABLE I. Demographic and Clinical Information (n = 47)

Sex	26 boys	21 girls
Mean age	14.5 years	(range 4–19)
Mean time since diagnosis	1.80 years (range 3 months–4.7 years)	
Treatment status	on therapy = 35 off therapy = 12	
Mean number of hospitalisations (over past year)	1.8 (range 0–12)	

A number of scales are available to assess symptoms in adults with cancer, of which one of the most widely used is the Rotterdam Symptom Checklist (RSC) [5]. The original scale consisted of 34 items, and was constructed from analyses of previous symptom rating scales. The original scale was subsequently reduced to 27 items, and two subscales described, measuring psychological distress and physical distress. Good internal reliability was reported for both subscales. Items are rated on 4-point scales. In the initial work, ratings were made over a period of 3–4 days, but in the final version, it was considered appropriate to extend this to the previous week.

Based on relatively large samples of adults diagnosed with a range of cancers, further reliability and validity data have been reported by Watson et al. [6]. The scale distinguished between patients who were undergoing chemotherapy and those who were not. The scale has the advantage of being simple and relatively quick to complete. Since it was developed for an adult population, it is based on self-ratings of symptomatology. In contrast, the need in pediatric oncology is very often for a scale which can be completed by parents, on behalf of their children.

In the absence of a measure developed specifically for use with children with cancer, we investigated the reliability and the validity of the Rotterdam Symptom Checklist (RSC) for use in paediatric oncology. Validity was established through comparison with two measures; the Play Performance Scale for Children (PPSC: 1) and the Functional Disability Index (FDI), a measure of daily activities [7].

METHOD

Ethical approval to conduct the study was obtained through the Royal Victoria Infirmary, Newcastle-upon-Tyne. The sample included 47 mothers of children with acute lymphoblastic leukaemia (ALL). Mothers were approached when attending routine clinic appointments, and asked to complete a questionnaire about “how their child was getting on.”

Demographic and medical data for the 47 children are shown in Table I. The majority (n = 35) were still undergoing routine maintenance therapy; the remainder were well and in remission.

TABLE II. Intercorrelations Between Measures

Symptoms	Physical symptoms	Psychological symptoms	FDI	PPSC
Physical		0.75***	0.51***	–0.64***
Psychological			0.55***	–0.53***
FDI				–0.56***

Materials

The Play Performance Scale for Children (PPSC) [1]. Mothers were asked to indicate the extent of their child’s activity, on a scale where 100 corresponds to “fully active; normal” through to 10, indicating that the child “does not play and is confined to bed.”

The Functional Disability Index (FDI) [7]. The original scale includes 15 items and is designed to assess difficulties experienced by the child in performing everyday activities (walking upstairs, doing homework). We excluded two items (run or walk the length of a football field), since pilot work suggested that British children had some difficulty with these items.

The Rotterdam Symptom Checklist [5]. We used the revised version described by Watson et al. [6]. Mothers were asked to rate their child in terms of both psychological and physical symptoms on a series of rating scales. As described in the above article, ratings were made over the previous week.

Demographic information. Mothers were asked to report the number of hospitalisations experienced by their child in the last 6 months. Age and sex, clinical data, including diagnosis, treatment status and duration of disease were taken from medical records.

RESULTS

Treatment of Data

All questionnaires were scored as described in the original articles. Validity of the RSC was determined by calculating correlations between RSC scale scores and scores on the PPSC and the FDI. Correlations were also calculated between scale scores and demographic and clinical data. Simple t-tests were used to assess the effect of treatment status and number of hospitalisations on subscale scores. Significance was accepted at the *P* > 0.05 level.

Reliability and Validity of the RSC Subscales

The coefficients for internal reliability were high for all scales, indicating good internal reliability (RSC physical = 0.86; RSC psychological = 0.87; FDI = 0.85). Intercorrelations between all scales were high (see Table II), suggesting that scores on the RSC correlate well with indices in more general use with paediatric populations.

TABLE III. Differences in Mean Scores on the RSC, the FDI and the PPS by Age (young = less than 7.3 years) and Gender

Symptoms	Age		t	Gender		t
	Young	Old		Boys	Girls	
Physical	1.62	1.48	0.73	1.51	1.58	-0.38
Psychological	1.77	1.59	0.77	1.70	1.65	0.19
FDI	1.98	1.55	2.03*	1.70	1.84	-0.61
PPS	84.54	85.83	-0.29	89.60	80.00	2.18*

* $P < 0.05$.

Physical and Psychological Functioning (RSC subscale scores) as a Function of (a) Age and Gender (Table III)

The group was divided on the basis of a median split (>7.3 years) in order to compare scores of younger and older children on the RSC subscales, PPSC and FDI. There were no differences in number of physical or psychological symptoms reported as a function of child age. However, mothers of younger compared with older children reported that the illness had greater impact on physical function (as reflected in scores on the FDI). Scores on the PPSC did not differ as a consequence of child age. There was only one significant effect of gender: boys achieved higher scores on the PPSC, suggesting they were rated as more active than girls.

(b) Treatment Status and Number of Hospitalisations (Table IV)

Children who had completed chemotherapy showed better functioning on the physical symptoms subscale, PPSC and FDI compared with children who were receiving chemotherapy. Similar results were obtained when comparing groups who had not experienced any hospitalisations over the previous 6 months, and those who had experienced at least one hospitalisation. However, there were no differences in psychological symptoms as a function of treatment status, or number of hospitalisations.

Correlations Between Scale Scores and Time Since Diagnosis and Number of Hospitalisations

Partial correlations were calculated to assess the relationship between the RSC subscales, the FDI and the PPSC with time since diagnosis and number of hospitalisations (controlling for child age). As time since diagnosis increased, fewer physical symptoms were reported ($r = 0.36$) and better functioning as indicated by FDI scores ($r = 0.32$) and PPSC ($r = 0.29$). There was no correlation between time since diagnosis and psychological symptoms ($r = 0.15$, n.s.) As the number of hospitalisations increased, there was an increase in physical symptoms ($r = 0.48$), psychological symptoms ($r =$

0.48), and poorer functioning on the FDI ($r = -0.41$) and PPSC ($r = -0.42$).

DISCUSSION

These data suggest that the Rotterdam Symptom Checklist has some applicability for use with children treated for cancer, in that significant correlations were found with other measures more traditionally in use with children. The physical distress scale discriminated successfully between children who experienced none or more than one hospitalisations over a 6-month period and between those who had completed therapy versus those still on chemotherapy. The RSC would therefore appear to have some value in determining symptom level in children with cancer; it is a brief instrument, easy to administer and shows discrimination as would be expected at least with respect to physical symptoms. It is less appropriate as a measure of psychological symptoms. There was no simple correlation between psychological symptoms and disease variables paralleling the findings with the physical symptom subscale.

Several reasons for this may be considered. First, it may be more difficult for parents to rate their child on psychological compared with physical symptoms. Although parents are likely to know whether or not the child has difficulty falling asleep or has lost appetite, they may be less likely to be aware whether or not the child feels anxious or worried. Some of the psychological symptoms (e.g., desperate) seem perhaps extreme and parents may be reluctant to apply such a label to a child. The present study does not allow us to conclude whether or not both subscales of the RSC would in fact be suitable where children were able to complete questionnaires themselves.

As is increasingly documented, psychological stress does not necessarily dissipate with the completion of therapy [8]. The psychological consequences of cancer, in terms of heightened anxiety and concern, can remain considerable, even when treatment is finished. A failure of the psychological symptoms subscale to discriminate between children who are on or off treatment may therefore not altogether be a criticism of the scale, but reflect a continuing high level of psychological distress.

A more general criticism is that mean scores for both physical and psychological subscales were low, indicating a lack of discriminability. Many children in our sample had either completed therapy or were well and in remission, and so would be expected to have relatively few symptoms. However, the group was a general cross-section of children attending pediatric oncology clinics, and as such would be expected to experience more ill health than healthy children. Further work needs to de-

TABLE IV. Differences in Mean Scores on the RSC, the FDI and the PPS by Treatment Status and Number of Hospitalisations

Symptoms	Treatment status			Hospitalisations		
	On-off therapy		t	None	>1	t
Physical	1.65	1.26	2.73**	1.36	1.90	-2.52*
Psychological	1.68	1.65	0.14	1.52	1.96	-1.59
FDI	1.91	1.36	3.20**	1.50	2.21	-3.41**
PPS	82.67	92.50	-2.17*	90.71	76.76	3.22**

* $P < 0.05$.** $P < 0.01$.*** $P < 0.001$.

termine if low ratings of symptoms are attributable to the lack of sensitivity of the RSC for use with children.

Although direct comparison with the results reported for adults by Watson et al. [6] is not appropriate, the data presented for adults also suggest that relatively low ratings were made. Thus, for their total sample, these authors report a mean score of psychological symptoms of 14.4 (based on a possible range of 8–32) and of 31.0 for physical symptoms (where the range is 18–112). Future work needs to pursue the implication of these low ratings. It may be that cancer patients expect to experience a degree of physical symptoms, and thus rate their discomfort more conservatively than would be expected.

In the absence of any other instrument, the RSC has the advantage of being brief and simple. Parents did not report that it was inappropriate. There is a need, however, for measures designed more specifically to assess symptoms in children with cancer. Assessments of symptoms are increasingly recognised to be an important and integral part of evaluation of clinical trials in order to provide a comprehensive picture of side effects of therapy. Without appropriate instruments, there is a tendency to rely on general measures of child behavior or function, or more cancer-specific measures designed for adult populations. Both have disadvantages. Progress in pediatric oncology is dependent on the development of measures which are focused specifically on issues of relevance to children with cancer.

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